Participatory technology assessment of xenotransplantation: experimenting with the Neo-Socratic Dialogue ; Austrian experiences

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Introduction

Like many developments in modern science and technology (Bonß 1995) xeno- or animal to human transplantation involves enormous potentials as well as high risks and serious ethical problems (e.g. OECD 1997, Hüsing 1998 et al. Schicktanz 2002). Such ethical problems are a major challenge to political decision-making mechanisms: how can they be appropriately and legitimately discussed and resolved? Are the usual democratic institutions adequate and is it sufficient to include only (bioethics)-experts in decision-making? Or do we need broader debates on ethics, involving also other actors as well as civil society. However, if a broad public discussion is necessary, how can we debate and resolve these questions, and which decision-making procedures can we use? This article presents first results of the Austrian part of an ongoing EU research project[2], which experiments with the Neo-Socratic Dialogue[3], (in the following NSD), a method for resolving ethical questions primarily used in teaching and consultancy, as a means of discussing ethical problems of xenotransplantation with the respective stakeholders.

In this discussion paper we will first sketch several ethical problems of xenotransplantation. Drawing on Marteen Hajer (2003), we will then distinguish several aspects of "institutional void" in the Austrian xenotransplantation "debate". In the next part we will outline the concept of NSD and we will describe the Austrian experiment to discuss ethical problems of xenotransplantation using the instrument of NSD. In the subsequent part we will present first evaluation results of this experiment and in the last part we will draw preliminary conclusions from our experiment.

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[2] The research project "Increasing Public Involvement in Debates on Ethical Questions of Xenotransplantation (XENO)" is funded by the European Commission, Research Directorate (Contract Nr. HPRP-CT-2001-00013). The project started in January 2002 and lasts two years. It involves the Fraunhofer Institut für Innovation und Systemforschung (Karlsruhe), the Freie Universität Berlin, the Consejo de Investigaciones Superior Cientificas (Madrid) and the Institut für Höhere Studien (Vienna). More information about the project can be found at: http://space.ihs.ac.at/departments/soc/xeno-pta. We wish to thank our European research partners as well as Margit Leuthold and Alexander Bogner for their contribution to the research project. We also want to thank Silvia Plaza for language editing.

[3] Based on the dialogues ascribed to Socrates, the modern Socratic Dialogue was developed by two German philosophers, Leonard Nelson (1882-1927) and Gustav Heckmann (1898-1996) from the 1920s onwards (Nelson 1965/1922; Birnbacher/ Krohn 2002, Raupach-Strey 2002). The prefix "Neo" denotes the various forms of Socratic Dialogue that have evolved since then through application of Socratic Dialogues in business and organization consultancy.

1 Ethical Questions of Xenotransplantation

Xenotransplantation means transplantation of non-human cells, tissues and organs into humans (Council of Europe 2000: 1). It is based on progress in transgenics and immunology, which have enabled the production of genetically modified animal organs that are more compatible with the human immune system, and also on improvements in controlling the human immune response. Xenotransplantation is associated with new risks and raises a number of major ethical problems (e.g. Melo et al. 2001). Though it could contribute to reducing the shortage of organs from human donors and thus save the lives of many patients waiting for transplantation, there is a serious risk that viruses causing animal diseases might cross the species barrier and spread through human populations (xenozoonosis). Ethical questions of xenotransplantation waiting to be resolved include, e.g.: Is it acceptable in principle, for reasons of religious belief, or because of cultural values, or considering animal welfare, to use animals as a source of organs and tissues for transplantation into humans? Which animals could be used (primates or non-primates)? Is it ethically acceptable to save the life of an individual while putting at risk health-care professionals, relatives and the general population because of potential epidemics? Is it acceptable to restrict the individual freedom of xenograft recipients to prevent epidemics and to protect public health?

2 The Austrian xenotransplantation “debate”

In the first step of our project we looked at the Austrian xenotransplantation debate in order to identify main issues and actors.

Between January 1995 and March 2002, the Austrian press published 145 articles about xenotransplantation and its potentials, as well as its medical, scientific and ethical problems. Reporting showed relative peaks in 1998 and particularly in 2000. Comparison with the number of articles on stem cell research published during the same period puts these figures into perspective. We noted that media coverage of stem cell research was higher each year than of xenotransplantation, particularly in 1999 and 2000.

Although Austrian newspapers and magazines did not completely omit the ethical questions of xenotransplantation, they referred to them rather incidentally. Some articles indicated vaguely the existence of *“ethical limits”* of research. Some simply pointed out that ethical questions existed (APA Journal Gesundheit 5.8.1998). The media did not present professional ethics experts to voice their opinions on the ethics of xenotransplantation. It was mostly physicians and surgeons who, in addition to their scientific expertise, also dealt with ethical questions of xenotransplantation. Journalists usually introduced ethical aspects of xenotransplantation incidentally and failed to develop and analyze the topic systematically. In other words, Austrian media did not examine and discuss the ethical aspects of xenotransplantation thoroughly.

As a second step we also asked (potential) stakeholders[4] several questions about the ethics of xenotransplantation (e.g. how the ethics of new technologies or xenotransplantation, respectively, should be addressed). In general, the respondents found it very hard to answer this question. Most of them told us frankly that this was a difficult question, some people did not answer at all and many of those who responded were not satisfied with their own answers.[5] With the personal interviews we pursued a twofold aim. On the one hand we wanted to investigate the stakeholders' positions towards xenotransplantation, and on the other hand we wanted to get into personal contact with the stakeholders to recruit them as participants in our Neo-Socratic experiment. Personal contact with potential participants seemed crucial to us, since Socratic Dialogues are not very well known in Austria and totally unknown in the field of technology assessment.

In summary, our investigation of the Austrian xenotransplantation "debate" showed that there was no public controversy on xenotransplantation in Austria.[6] At present, both the intensity and content of debate are undeveloped by international comparison.[7] Not only the general public but also most political and administrative authorities are comparatively unaware of a potential controversy on xenotransplantation. Several reasons might be responsible for this, but since Austrian public and private research is not active in this field, there is no immediate reason for debate.[8] Austria shows a relatively high number of organ donations[9] and therefore

[4] This group included researchers, transplantation surgeons and representatives of self-help groups, public administration staff, animal welfare proponents, churches, insurance companies and the media as well as patient ombuds-persons.

[5] As one respondent said, there is general agreement that broad consensus on these issues is needed in our society, but people are hardly ever able to say how this consent can be achieved.

[6] Detailed information on discourse analysis in the three participating countries (Austria, Germany and Spain) is published on the project homepage: http://space.ihs.ac.at/departments/soc/xeno-pta

[7] European countries vary considerably regarding their awareness of xenotransplantation and the intensity of debate. While some countries have already set up expert commissions to investigate the problems of xenotransplantation and have started to issue some guidelines, e.g. in the United Kingdom (Advisory Group 1996), The Netherlands (Gezondheidsraad 1998), Germany (Petermann/ Sauter 1999) and Sweden (Swedish Committee on Xenotransplantation 1999), Austria, like many other countries, has not dealt with the topic so far.

[8] Austrian transplantation surgeons do not carry out xenotransplantation research, but the three Austrian university hospitals keep informed on international research results. The Austrian subsidiary of Novartis, the leading company conducting xenotransplantation research, is not active in this field itself but is a producer of immunosuppressive drugs.

[9] The number of donors per million inhabitants and thus number of available organs differs significantly across Europe. Austria is third after Spain and Belgium measured by the number of donors per million inhabitants (Spain, 33,9, Belgium 25,6, Austria 24, Germany 12, Sweden 10,9; Council of Europe, Transplant Procurement Management (TPM), February 2002; Eurotransplant. Quoted in: ÖBIG 2002: 31).

– despite existing waiting lists[10] - organ shortage might be less urgent than in other European countries. Potential opponents of xenotransplantation seem to be absorbed in the GMO-food debate and have not initiated a discussion yet. So far, mainly the risk that animal diseases might spread to the general population is perceived as topical. Ethical, psychological and financial questions are almost not debated so far.

It is possible to distinguish four different aspects of "institutional void" in this context. First, the topic of xenotransplantation was not very visible in the Austrian media. The newspapers did not cover such issues very intensively. This might be due to the fact that Austria does not have a strong tradition of public debate in general and on controversial scientific and technological issues in particular. Moreover, there are not many Austrian quality papers, e.g. in comparison to Germany and Switzerland, which could act as a forum for such a debate. Second, when there was xenotransplantation reporting at all, ethical questions were rarely touched. Third, although international bodies as well as advisory and political bodies in other countries addressed xenotransplantation (e.g. Council of Europe 1997 and 2000, OECD 1997, WHO 1998), so far no Austrian body in public administration and politics has dealt with the issue in depth. Finally, it is quite unclear for the potential xenotransplantation stakeholders which forum should address the ethics of xenotransplantation and how this should be done.

3 What is Neo-Socratic Dialogue?

The initial idea of the XENO project was to experiment with and evaluate an instrument enabling both experts and laypersons to enter into a systematic investigation of the ethics of modern science and technology. In this way it should be possible to broaden the debate on ethics beyond the group of scientific experts and experts in bioethics. For this purpose the instrument of the Neo Socratic Dialogue (NSD) appeared to be most promising to us. In the following section we will explain the concept of NSD in greater detail.

NSD is an inquiry into ideas meant to establish consensus on a given topic through joint deliberation and the weighing of arguments. NSD aims at envisaging, at explaining values and clarifying fundamental concepts. It implies a systematic investigation of viewpoints, assumptions and reasons, and a cooperative way of testing their validity. Through NSD, participants try to formulate legitimate principles and they develop a shared and inspiring perspective (Nelson 1922, 1965, Heckmann 1993).

NSD focuses on a single fundamental ethical or philosophical question, which should concern basic, essential issues and should be non-empirical, i.e. answerable by thinking only. The participants should be committed to the inquiry, in other words the debated question must be personally important to them. The question must be formulated in such a way that participants can find relevant examples from their own everyday life. The issue investigated by NSD must

[10] Despite the high number of transplantations between January 1996 and December 2001, approximately 130 Austrian heart patients died while on the waiting list for transplantation (ÖBIG: 2002: 41).

play a key role in those examples. NSD is applied to one concrete experience of one of the participants which is accessible to all other participants. Systematic reflection about this experience is accompanied by a search for shared judgments and their underlying reasons. Participants in NSD do not need specialized or expert knowledge of the question at hand. Rather, the empirical material of the Socratic investigation (i.e. the examples and judgments expressed) forms the basis for joint reflection on the implicit values, principles and preconditions of everyday action. The number of participants in NSD ranges from a minimum of five to a maximum of fifteen people.

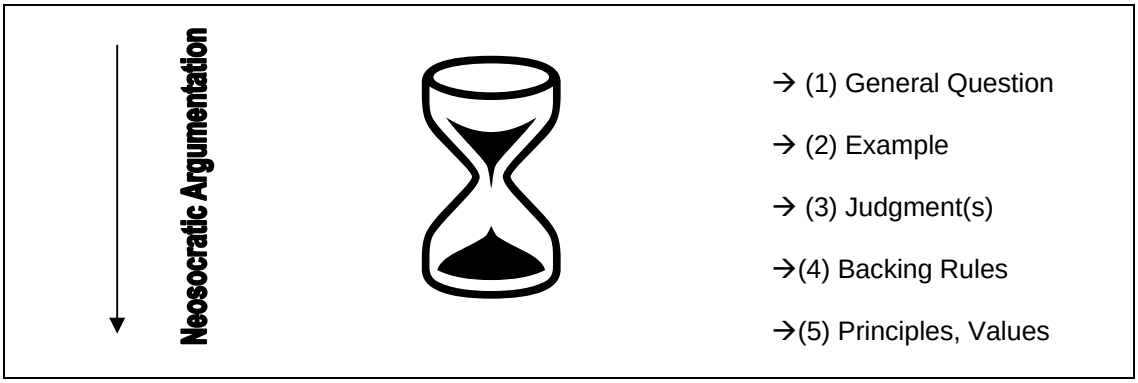
The second aim of NSD is to improve the participants' skills in carrying on stringent discourse, such as listening to and referring to each other, tolerance, striving for mutual understanding. This requires adequate command of a number of dialogical roles, skills and attitudes, especially suspending judgment and maintaining a balance between taking a position and giving in.

NSD has been applied successfully in organizational learning (Kessels 1996), business ethics (Kessels 1997/2001), medical ethics (Birnbacher 1999), university teaching (Heckmann 1993, Birnbacher 1982, Kleinknecht 1989, Gronke/Stary 1998, Littig 1999 and 2003), as well as in primary education (Weierstraß 1967, Murris 2000).

The specific structure of NSD consists of the following steps: (1) Before NSD starts, a well-chosen, general question must be formulated. (2) In the first phase, the participants give concrete examples from their personal experience in which the set question plays a key role. (3) In the next phase, the group selects one example, which will become the basis of analysis and argumentation throughout the NSD. The analysis usually starts with passing one concrete judgment on the selected example and relating it to the original question of the dialogue. (4) During NSD, the participants examine the validity of the judgment/ statement step by step.

From an epistemological perspective, the systematic examination of arguments through NSD is guided by the idea of regressive abstraction. This concept indicates that individual insight is gained from concrete judgment and personal experience (Nelson 1965). According to argumentation theory, concrete judgments must be backed by more general rules or principles, which again stem from a higher argumentative level than the judgment itself (e.g. Toulmin 1958). The idea of regressive abstraction can be illustrated by the Kessels' sandglass model (cf. Figure 1):

Figure 1: Regressive Abstraction: the Sandglass Model



(Kessels 1997/2001: 205; English translation by the authors)

The sandglass model depicts the concept of regressive abstraction in the following way. The *general question* is the starting point and focus of NSD. The *example* provides the necessary facts, circumstances and actions/decisions, which have been taken in a single case. The *judgment* represents a standpoint, which has to be examined during the NSD. The *backing rules* provide the reasons given for the judgment. The *principles and values* again give reasons for the rule(s). The aim of NSD is to discover the backing rules and to discuss the validity of rules and principles regarding the particular example. In the context of NSD on xenotransplantation it was necessary, first, to find and formulate one general question related to the ethical problems of xenotransplantation. Second, the principles and values uncovered through NSD had to be applied to the concrete issue of xenotransplantation.

4 Austrian NSDs on Xenotransplantation

In October and November 2002 we organized two experimental Austrian NSDs on ethical problems of xenotransplantation.[11] Since discourse analysis showed that the risk of epidemics (beside others risks, see Table 1) was a key issue in the xenotransplantation debate in all three countries taking part in the study, we dedicated all dialogues to the ethics of risk. Thus, the project team formulated “What risk to take?” as preliminary question for the NSD.

All participants of the two NSDs were stakeholders in the field of xenotransplantation, i.e. people actively involved in research, decision-making and funding of xenotransplantation, or they were representatives of groups potentially involved in xenotransplantation, either as patients and relatives of patients, or as members of relevant NGOs. In Austria we identified more than thirty stakeholders as potential participants in NSD, who came from research, medicine, government agencies, political parties, firms, patient self-help groups, patient

[11] In January and February 2003 another four NSDs were carried out in Spain and Germany. The NSDs were conducted by trained facilitators of the German GSP (Gesellschaft für Sokratisches Philosophieren, http://www.philosophisch-politische-akademie.de). In Austria the facilitator was Beate Littig, in Germany it was Horst Gronke and in Spain it was Paolo Dordoni (still being trained).

ombuds-persons, religious groups, environmental and animal rights groups, health insurance representatives, as well as the media.

In NSD1 there were eight, in NSD2 ten participants. NSD1 involved three physicians[12], two representatives from a transplantation self-help group, one representative of the Austrian Ecumenical Council, one representative of an animal rights group and one regional patient attorney. The participants in NSD2 were two scientists (virologist, immunologist), one representative of a private health insurance company, one psychologist working with transplant patients, one kidney-transplant patient, one science journalist, two representatives of government agencies with science backgrounds, one animal rights activist and one representative of an international pharmaceutical company active in xenotransplantation research.

In the evening, before the start of the actual NSD, there was an introductory meeting. This evening program included a general introduction to the project and its goals, explanations on discourse analysis as well as an introduction to the theory and practice of NSD. The participants were then asked to agree on one common question for the dialogue. In the discussion about what question to take, the participants of both NSDs modified our preliminary question “What risk to take”?” to “What risk are we allowed to take?”. They decided to take the second, more open, formulation representing a more cautious approach towards the risks of xenotransplantation (XTP). By contrast, the question “What risk do we have to take?”, which was also considered, appeared to be much more narrowly defined: it implies that risks have to be taken without further deliberation.

Subsequently, the participants discussed a list of potential risks of xenotransplantation, which the NSD facilitator had previously prepared on the basis of literature review and interviews (cf. Table 1). This list was also used in the final phase of the NSD on XTP, i.e. the NSD results were related to the ethics of xenotransplantation. We had planned to carry out a “traditional” NSD, i.e. to work with some everyday experience shared by all participants. The reason for not taking a topic from the field of XTP was that organ transplantation is still at the research stage with animals and is not yet being tested in humans. Examples discussed would then come from the sphere of medical experiments, which perhaps not all participants would be able to comprehend. In addition, we wanted to get away from the field of XTP to create a more relaxed atmosphere for the dialogue. It had been evident from our expert interviews that some of the participants had diverging and conflicting opinions with respect to XTP.

[12] This subgroup included one transplantation surgeon, a physician involved in research on alternatives to animal testing and a member of parliament of the Green Party.

Table 1: Xenotransplantation Risks

If xenotransplantation is pursued	If xenotransplantation is not pursued:
Risk • of infectious epidemics • of impairing freedom rights (e.g. quarantine) • of a totally instrumental society-nature relationship • of impairing human self-understanding • of neglecting basic medical support in favor of high-tech medicine • of widening the gap between rich and poor countries in regard to supply of medical care • of identity problems or social discrimination of xenotransplantation patients • of decreasing public willingness to donate organs *Participants' additional contribution in NSD 2:* **Risk** • that during the initial clinical trials xenotransplantation therapy is worse than the disease itself • of misplaced resource allocation • of less compliance in xenotransplantation patients than in allograft patients	**Risk** • of people dying, who before being able to could receive xenotransplantation organs • of not improving the patients' quality of life (dialysis) • of boosting organ trade

The actual NSD on the next day lasted for six hours. It started with the collection of empirical examples related to the question "What risk are we allowed to take?" After the selection of one suitable example and its subsequent analysis, the person providing the example expressed his/her personal judgment on it. The example in NSD1 was risky car driving. In NSD2 it was some risky advice given in animal husbandry consulting; the supplier of the example had advised a farmer not to cut off the horns of cattle kept in free-range husbandry. Later, a cow injured the farmer seriously. The final hour of the dialogues was reserved for applying the dialogue findings to xenotransplantation.

The argumentation phase of NSD1 commenced with the example-giver's judgement on her risky car-driving: She stated that she had taken the risk since the goal (happiness/ love-affair) was worth it. She explained that she had paid less attention to the risk than to the goal. Most participants shared the view stated by the example-giver, although she later thought that her risky car driving had not been justified. In relation to this statement the argumentation of the group turned to the risk side of the example, trying to find criteria for legitimate risky behavior. The idea that risky behavior could be justified by the positive outcome of an action did not get much support. The group finally agreed on the statement that risks can be taken if the potential damage is reversible. This thought was developed further by the following consideration: If the aspired aims are useful for more people than those likely to suffer from

the respective negative effects, those aims can be pursued. But the actions taken to reach the goal must be evaluated and controlled to minimize the risks involved. This stated view provoked a lengthy discussion about justified quantitative and qualitative effects, i.e. about the relationship between benefits and damage or loss brought about by risky actions. The participants examined whether this relationship can be defined in quantitative terms at all, especially in cases where the negative effects can only be roughly estimated via statistical probabilities. They expressed doubts whether, in the case of XTP, a low probability of xenozoonosis occurring would justify the risk of severe damage affecting entire populations. How to deal with this situation from an ethical point of view?

At the end of the dialogue, the group of NSD1 arrived at a consensus on the question "What risk are we allowed to take?". The participants agreed on the general statement that the relationship between potential harm and expected benefit must be clearly positive on the side of benefit.[13] The participants then applied this general rule to three risks of xenotransplantation that they selected from Table 1 (risk of infectious epidemics, risk of a totally instrumental society-nature relationship, risk of neglecting basic medical support in favor of high-tech medicine). In principle, the consensus statement proved to be applicable to the selected XTP risks. But during the discussion it turned out that the decision about the legitimacy of risk-taking, when applied to concrete cases, would require detailed information in every single case (e.g. on the financial situation of the health care system).

In contrast, the participants in NSD2 did not reach agreement on a common statement. The reasons for this lie in the very different process of NSD2. In this case, it turned out to be much more difficult to engage people in the dialogue and in a discussion of ethical questions. The participants in NSD2 were rather reluctant to consider the question of the dialogue in the light of their personal experiences and values. This already became apparent during the first phase of the dialogue, when most participants did not introduce personal examples from their private lives but rather from their professions.

The argumentation phase of NSD2 started with the example-giver's statement that he took the risk (giving advice with respect to free-range husbandry) because he placed the ideology of animal rights above human well-being. Contrary to that past episode, he later found his action no longer justified. All participants shared his personal judgement of non-justification. Being instructed by the facilitator to give their own reasons for their judgements the participants came up with reasons revolving around the following ideas:

- The necessity of considering probabilities in risk assessment (probability of occurrence of negative effects, gravity of damage, expected benefit)
- The legitimacy of ideologies or idealistic attitudes in decision-making

[13] In German the wording of the sentence was: "Die Verhältnismäßigkeit des möglichen Schadens zum zu erwarteten Nutzen muss deutlich zugunsten des Nutzens liegen."

- Does the actual result of a risky action justify or question the previous decision to take the risk?

The group decided to examine more closely the first of the above items related to the concept of risk assessment. But, instead of analyzing the every-day example presented by one participant, some group members able to influence the others stuck to their professional idea of quantitative risk assessment as solution for decision-making problems related to risky technologies. They did not think that systematic ethical considerations (as proposed by NSD) were appropriate to contribute to decision-making with respect to XTP. Instead, they wanted to discuss the topic of xenotransplantation without the supposed ethical "deviation". They refused to follow the facilitator's interventions to return to the analysis of the chosen example. In the end, the group did not come up with any final statement to the ethical question "What risk are we allowed to take?" Therefore, they were not able to apply a common statement on risk to a debate of ethical questions concerning xenotransplantation at the end of the dialogue.[14] The main outcome of NSD2 was, on the one hand, a prolonged meta-discussion at the end of the dialogue whether NSD is appropriate for discussing – as they put it - the "real" question of XTP. On the other hand, they started to draw up a list of several problematic aspects of XTP (economic, psychological and social ones), which turned the event into something more like a brainstorming session rather than a dialogue.

5 Participant feedback

In the following section we present the first evaluation results of the two Austrian NSDs[15].

We assumed that NSD could only be called a useful instrument in public debate if it is able to facilitate dialogue on issues about which people have strong feelings. Therefore, we asked whether or not the participants felt personally involved in the topic of xenotransplantation. In all, 72% of the participants felt to have either a strong or medium connection with xenotransplantation. About 17% felt a minor involvement in xenotransplantation only and one person felt to have no connection at all with it. The share of people who felt to have a strong and medium connection with xenotransplantation was almost equal in NSD1 (75%) and NSD2 (70%). However, the share of people who felt to have a strong connection with xenotransplantation was larger in NSD1 than in NSD2 (38% versus 20%). In NSD1 one person felt to have only a minor connection with the topic, whereas in the second NSD two

[14] A more detailed analysis and comparison of the processes involved in the two dialogues, as well as a comparison with the two Spanish and the two German dialogues will be a key focus of our ongoing research project.

[15] For this evaluation, we *inter alia* asked the participants to fill in two questionnaires, one before the start the other at the end of the NSDs. In the first questionnaire, we asked the group members about their motivation for participating in NSDs, their personal knowledge about xenotransplantation, their judgment about ethical issues involved in xenotransplantation as well as for some statistical data. In the second questionnaire, we primarily asked the participants about their experiences and for an assessment of the NSD in which they had participated.

people reported to have a minor connection while one person stated to have no connection. Thus, xenotransplantation was an important topic for a clear majority of participants.

Another factor possibly influencing NSD is the participants' personal level of information about the topic under discussion. In all, a large majority, i.e. 83% of the participants, thought they were fully or fairly informed about xenotransplantation. Nobody considered himself or herself to be uninformed. In NSD2 the share of participants considering themselves as fully or fairly informed was higher than in NSD1. In NSD2 30% thought they were fully informed, 60% fairly informed and 10% little informed. The respective shares in NSD1 were 25% fully informed, 50% fairly informed and 25% little informed.

Conflicting views on the topic under discussion are typical for discussions on ethics. This was also the case in our NSDs, indicated by the responses to the question about the desirability of xenotransplantation as a future method of medical treatment. In both NSDs, 50% of the respondents agreed very much, or rather agreed, with the statement that xenotransplantation is a desirable future method of treatment. In NSD1 one person did not agree with the statement and another person did rather not agree. In NSD2 the respective share of respondents was 20%. In NSD2 the share of undecided persons was slightly higher (30%) than in NSD1 (25%).

To recapitulate the starting point of the NSD: an absolute majority of the participants of the two NSD thought to have a strong or medium connection to XTP; a large majority considered themselves as fully or fairly informed about XTP and 50% of them agreed very much and rather that XTP was a desirable future method of treatment.

The participants expected from the NSD an exciting discussion regarding content (67% very high expectations, 22% high expectations) and an open discussion (44% very high expectations, 50% high expectations). Furthermore, they wanted to get acquainted with a form of discussion differing from the usual one (50% high expectations, 39% high expectations) and expected a clearly structured conversation (44% very high, 44% high expectations). They also expected an equal dialogue among all participants (61% very high, 22% high expectations), a high-level conversation (44% very high, 39% high expectations) and to get to know other people and their points of view (44% very high, 39% high expectations). They also expected to improve their understanding of other participants' standpoints (22% very high, 61% high expectations).

In summary, to conceptualize the participants' expectations, the majority expected an exciting discussion with respect to content in an open atmosphere. They expected that the discussion would be clearly structured and would differ from the usual forms of discussion; also, that it would allow an equal dialogue among participants interested in the topic of xenotransplantation. NSD would be a high-level discussion and participants would get to know and understand other group members' opinions. Comparatively few participants expected to reach consensus on xenotransplantation or to modify their own standpoints (11% very high expectations with respect to both questions).

To which extent were these expectations met? Adding up the two NSDs, 61% of the participants thought that their expectations were surpassed, met or rather met. 28% of them thought that their expectations were surpassed, 22% that they were met and 11% that they were rather met. But 22% of the participants thought that their expectations were not met.

What did the participants gain from taking part in NSD? First, there was a group of expectations, which many participants had had that were more or less met. This group included “open conversation” (17 “very high” and “high” expectations/ 16 “agree very much” and “agree”), “to have the possibility of getting to know a different form of discussion from the usual one” (16 expected /17 fulfilled), “dialogue equal for all participants” (15 expected /17 fulfilled), “high-level conversation” (15/16), “other participants’ interest in the topic” (15 expected/13 fulfilled), to “to become acquainted with other people and their standpoints“, (15 expected/13 fulfilled) and “time to think about an ethical problem” (11 expected/12 fulfilled). Except for the expectation “to gain new insights into the ethics of xenotransplantation” (17 expected/14 fulfilled) this group of expectations had to do with the process of NSD.

Second, we were able to distinguish some major issues that were not met to the same extent as previously expected. This cluster included “exciting discussions” and “clearly structured discussion” (16 expected /11 fulfilled each), “better understand other positions” (15 expected /10 fulfilled) and “new information about XTP” (9 expected /4 fulfilled). In particular, the expectation “to get to know NSD” (15 expected /4 fulfilled) was dramatically missed. Most of these shortfalls – with the exception of the expectation “to get to know NSD” - can be attributed to NSD2. Whereas 75% of NSD1 respondents said that their expectations of an “exciting discussion” were fulfilled, the respective NSD2 share was only 20%. The ratio was 88% to 40% with respect to “a clearly structured discussion”, 88% to 30% concerning “to better understand other positions” and 38% to 10% with respect to “new information about XTP”.

Third, a small number of expectations were strongly exceeded. Although only 5 participants expected “that other participants (will) refer to my arguments”, 12 people said, “other participants referred to their arguments” (75% in NSD1 and 50% in NSD2). There was a ratio of 5 expected /10 fulfilled with respect to the expectation that “other participants (will) listen to me and try to understand” (63% in NSD1 and 50% in NSD2).

Fourth, there were some issues on which expectations were met for a small number of participants. This group includes output oriented issues such as “a clear answer how to deal with XTP” (3 expected/4 fulfilled), “to reach consensus concerning xenotransplantation” (2 expected /3 fulfilled), “to change my position concerning xenotransplantation” (2 expected /3 fulfilled), “to convince others” (1 expected /3 fulfilled).

If we look at differences between NSD1 and NSD2 concerning fulfilled expectations, we can again see that the participants of NSD were more satisfied with the NSD than the participants of NSD2. With few exceptions, the share of participants that saw their expectations fulfilled was higher in NSD 1 than in NSD.

NSD1 and NSD2 differed very much with respect to meeting participants' expectations. In NSD1 50% of the participants thought that their expectations were surpassed and 38% that their expectations were met. Only one person felt that NSD did not meet his/her expectations. In contrast to this quite positive result, in NSD2 30% of the participants thought that the dialogue did not meet and 30% thought that the event rather did not meet their expectations.

The NSD did not change the participants' views or judgments. Only one person of the 18 participants mentioned that the NSD changed his opinion on xenotransplantation.

To what extent were the results of the two NSDs useful for the participants? Altogether, 50% of the participants considered the results of NSD as very or rather useful for their work. However, again, there was a striking difference between NSD1 and NSD2. In NSD1 38% of the participants considered the results as very useful and 50% as rather useful. In contrast to this, nobody in NSD2 considered the results as very useful and only 20% as rather useful, but 20% thought that the results were rather not useful and 60% that they were not useful for their professional or voluntary work.

A useful way of finding out about people's judgments is to ask them to assign school marks. Thus we asked the participants to assign school grades on their respective NSDs. Again there was a sharp difference between NSD1 and NSD2. In NSD1 50% of the participants assigned the grade excellent and 38% the grade fair. In contrast, in NSD2 30% of the participants assigned the grade fair, and 20% each assigned the grades satisfactory and sufficient. One person assigned the grade unsatisfactory.

We assumed that willingness to recommend an event to an interested colleague is a rather strong quality indicator. This assumption is based on the idea that the recommendation connects the recommended event with the recommending person's reputation. In other words, a recommendation puts the recommending person's reputation at stake. Thus, we assumed that people are more cautious with recommendations to peers than with assigning grades.

More than 77% of all participants would either very much or rather recommend NSD to an interested colleague. In NSD1 altogether 88% would either very much or rather recommend NSD. The share of participants in NSD1 who would recommend NSD was 75% and only one person would not recommend NSD to an interested colleague. In contrast, participants in NSD2 were less willing to recommend the event. Altogether, 70% would very much or rather recommend NSD to an interested colleague. However, only one person among them would recommend NSD very much, the remaining 60% would rather recommend the event and 30% of the participants would rather not recommend NSD to an interested colleague.

6 Résumé and outlook

In the final section of this paper we return to the previously identified four aspects of institutional void in the Austrian xenotransplantation debate and we discuss the way in which

our project could contribute to improving this deficiency. We shall also touch upon problematic aspects of NSD revealed through our experiment and mention our future research interest.

Aspect 1: Lack of Public Debate in the Media

The creation of media awareness for xenotransplantation had not been our project's main research interest. Rather, we had wanted to experiment with a method of discussing the ethics of modern medicine with concerned stakeholders. Naturally, journalists belonged to the stakeholders we were looking for. We addressed reporters working for a quality newspaper, a weekly magazine and for Austrian radio. As a result, the project was mentioned on the radio and in a weekly magazine and it also stimulated an additional radio program on xenotransplantation. Additional stimulation of public debate in the media will largely depend on further dissemination activities.

Aspect 2: Minor importance of ethical aspects of xenotransplantation in reporting

It turned out to be particularly hard to get journalists to participate in NSD. The reason for this might be time pressure and, judging from the media analysis and the interviews, also the fact that most journalists were less concerned with the ethics of xenotransplantation than with its potentials and obstacles. Thus, to raise the awareness of reporters about the ethics of xenotransplantation will remain an important task in the dissemination of project results.

Aspect 3: Political institutions and NGOs

In the course of the project we discussed the ethics of xenotransplantation with stakeholders in public administration, politics, interested organizations, self-help groups and patient ombuds-persons. Eighteen of them also participated in the NSDs. This certainly raised some awareness in the respective institutions. To strengthen awareness further remains a task for the dissemination phase of the project. However, like other methods of participatory technology assessment, the legitimacy of such an exercise and its connection with political decision-making is not direct and unclear. Also, in our experiment, dissemination of NSD results in the participants' organization was unsystematic and was left to the participants' initiative. In future, it will be necessary to find ways of integrating NSDs in existing institutions.

Since the focus of NSD is on ethical implications and problems, which obviously does not cover all aspects of political decision-making, it could be useful to integrate NSD in existing decision-making mechanisms and to combine it with other participatory methods, such as consensus conferences (Joss 1999, Joss/ Durant 1995, Joss/ Belucci 2002).

Aspect 4: How to debate ethical issues of new technologies?

The result of NSD1 and the responses of its participants proved that NSD is an instrument that could help stakeholders to discuss the ethics of xenotransplantation. In all, two-thirds of the participants in NSD1 and NSD2 considered the method very useful or rather useful for their work. A particular strength of NSD is that it enables both laypersons and experts to

engage in systematic reflection of the ethics of science and technology. But we learned from NSD2 that certain preconditions must be fulfilled to make NSD work. NSD is certainly not a method useful for every topic and for everybody. The requirements for successful NSD have to do with the participating individuals and with the particular debate. NSD participants must have certain individual qualities and skills. NSD requires what one could call "open-mindedness" in the participants, i.e. willingness to show and to evaluate their own standpoints and values on the basis of their own experiences and not according to "textbook" theories. This is totally different from the usual conception of professional expertise and, as NSD2 proved, not a natural process. On the level of debate, the intensity of conflict might be an important criterion for the successfulness of NSD. If the intensity of conflict and/or of the participants' unwillingness to show and question their own values make NSD impossible, other forms of debate or decision-making such as mediation, bargaining or decision-making by law courts may be more appropriate. Further research is needed on the preconditions for successful NSD, both with respect to the individuals involved and to the debate itself.

Just as with other new methods of participatory technology assessment, the representativeness of the participants for the general population is a weak point. In our experiment, we did not attempt to choose the participants at random, but we tried to get at least one representative from each stakeholder group, since the small number of participants enabling direct face-to-face communication strongly limits representativeness.

Moreover, it was difficult to find people willing to participate in the discussion. Altogether, we asked 34 Austrian stakeholders to participate in the project. All of them, except one, immediately agreed. However, in the end, only 18 people showed up for the NSDs. We interpret this dropout rate of 47% that stakeholders tend to pay lip service to the importance of ethics in science and technology but that they rate these issues as secondary under conditions of time pressure. Many stakeholders said they would wish to have more time for discussing such topics, but experience shows that it is hard to find participants who will take the time to discuss this issue for as much as one day.

It is important to stress that NSD on the ethics of xenotransplantation is not a discussion on risk assessment, but a dialogue on ethical questions and problems of xenotransplantation. Therefore, it is necessary to start the dialogue with a short introduction on general ethical questions, e.g. *"What distinguishes ethical questions from knowledge questions and where are the differences in approaching them?"* This information is necessary since participants in this context are not familiar with NSD. In many cases, they are not even familiar with the fact that *ethics* is involved in xenotransplantation, even though many of them consider themselves to be well informed on the subject.

So far, we are only in the early stages of evaluating the NSDs carried out in Austria. Further analysis of the ex-ante and ex-post questionnaires, of interviews with participants and of records on the dialogues, as well as comparisons of our results with the German and Spanish evaluation outcomes will further clarify the preconditions for successful NSDs in the special

setting of science and technology and the contribution it can make to fostering democratic debate of these issues.

7 Literature

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